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ABSTRACT

This guide on Alzheimer's disease is for those who care for Alzheimer's patients, as well as those who want to learn more about the disease. It answers these questions: (1) what is Alzheimer's? (2) how does the disease progress and how long does it last? (3) how do families cope? and (4) who can provide assistance and information? The guide also describes Alzheimer's support groups, long-term care, and the outlook for the future. The first topic discussed is the nature and history of Alzheimer's disease, including symptoms, course of the disease, diagnosis, acceptance and denial, emotional devastation, and history of the disease. Treatment and caregiving issues are discussed, including at-home care, respite care, and nursing homes. Providers of financial help are described. Research in Alzheimer's disease is discussed. Resources available from the American Association of Retired Persons and others are listed and described. (ABL)

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Coping & Caring

LIVING WITH ALZHEIMER'S DISEASE

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Written by Charles Leroux

A.D.™ Alzheimer's Disease and Related Disorders Association, Inc.

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"Healthy US" is the major national campaign of the American Association of Retired Persons to help reduce the skyrocketing health care costs that are weakening our health care system and our national economy. The campaign includes political and consumer action, and health promotion activities. To learn how you can help, write: "Healthy US," AARP, 1909 K Street, NW, Washington, DC 20049.

Dear Friend:

"Alzheimer's disease." It's a phrase that often provokes concern, uneasiness, anxiety and misunderstanding. It affects men and women, black and white, rich and poor, brilliant minds and average ones. Most of you probably know a family now dealing with Alzheimer's disease. Because of this, AARP has joined with the Alzheimer's Disease and Related Disorders Association (ADRDA) in an attempt to dispel the myths, calm the fears, and increase the understanding of Alzheimer's disease.

It has been said that victims of Alzheimer's are both the patient and the caregiver.

"Coping & Caring" is for those who care for Alzheimer's patients, as well as those who want to learn more about the disease. It answers these questions:

- What is Alzheimer's?
- How does the disease progress? How long does it last?
- How do families cope?
- Who can provide assistance? Information?

In addition, this guide describes Alzheimer's support groups, long-term care, and the outlook for the future.

The news about Alzheimer's is not all grim. Researchers are coming closer to understanding its causes and to better treatments. Groups like ADRDA have organized to support Alzheimer's families and to advocate increased funding for research and equitable treatment of the Alzheimer's patient by the medical system. And families of Alzheimer's patients share the positive and rewarding aspects of caring for their loved ones.

This booklet has been produced as part of AARP's HEALTHY US campaign to provide consumers with information about the important health care issues which affect their lives. "Coping & Caring" may provide you with the answers you need about Alzheimer's. I hope you will read it carefully and share it with friends or loved ones who could benefit from the information.

Sincerely,

Cyril Brickfield
Executive Director

THE NATURE AND HISTORY OF ALZHEIMER'S DISEASE

Some Discomforting Statistics

"I thought that the doctor was saying, 'OLDTIMER'S disease,' many relatives of Alzheimer's disease patients say now, recalling when they first were told a diagnosis. "It sounded benign," they say, "sort of cute, like when you can't find your glasses because you've forgotten you have them on."

All too soon, they found out that there is nothing benign about Alzheimer's.

It is a dementing disease, a thief of minds, a destroyer of personalities, wrecker of family finances, filler of nursing homes. It also is a killer, the fourth leading cause of death for American adults (after heart disease, cancer, and stroke) accounting for 150,000 deaths a year. It respects few boundaries. The estimated 2.5 million Americans afflicted by Alzheimer's disease are male and female, black and white, rich and poor, city dwellers and farmers, brilliant and average. It can strike people in their 40s; in rare cases, their 20s; but most victims are among the growing number of Americans who reach and surpass their 65th birthdays. Of these, Alzheimer's affects some 7 to 9 per cent.

A Growing Problem

In 1980, Dr. Carl Eisdorfer, then-chairman of the department of psychiatry and behavioral sciences at the University of Washington School of Medicine, testified before a joint Congressional hearing. He noted that *"For most of the century, what we have done is primarily to increase the life expectancy of people at birth and relatively little to change the life expectancy of the 65-year-old. In the last decade, we have begun to see...the aging of the aged. During the period 1970 to 1977 inclusive, the number of Americans over the age of 75 increased by a phenomenal 39 per cent. This growth rate is continuing...Unfortunately, but absolutely predictably, among the more negative aspects of this population increase will be a concomitant increase in (Alzheimer's disease)."*

A few years later, the government confirmed the truth of Eisdorfer's warning. Margaret Heckler, then-Secretary of the Department of Health and Human Services, said: *"Given the threshhold blessing of longer lives, the important question then becomes how healthy, active, and independent our older years will be. Even as the proliferation of medical miracles and ever-improving health care have been major contributing factors in this ongoing transformation of our national 'profile,' too many of our people still fall prey to serious illness. None is more terrifying and life altering for the elderly than Alzheimer's disease."*

Symptoms

This terrible thief of minds that ends as a killer begins as a petty criminal. Perhaps the ability to make change suddenly seems to be missing, or the memory of names may be misplaced. These kinds of lapses can happen to anyone, of course, and for most people there is no reason to suspect—or fear—Alzheimer's. After all, the disease DOES NOT affect some 91 percent of those over age 65.

For some, however, the gaps in memory grow wider and deeper: "That thing in my hand (his house key). I have no idea what to do with it."

Or, "I know I live near here, but I don't know which way to go."

Or even, "That man (her husband). Who is he?"

The Alzheimer's disease victim will suffer changes in memory, thought, personality, language, and more. These changes won't happen all at once, but rather over time since Alzheimer's is a progressive, degenerative disease. In other words, it gets worse and worse and leads, ultimately, to death, usually due to a secondary infection. The course of the illness varies from individual to individual. There can be plateaus, stretches of time in which losses seem to level off; and there can be relative "good" and "bad" days. All in all, however, the disease follows a more-or-less predictable, relentless course.

The Course of the Disease

It begins almost imperceptibly; an inability to find the right word, especially nouns, a growing tendency to write many reminder notes, to wear the same clothes day after day, to depend on family members to fill memory gaps, and to blame all the lapses on fatigue, stress, grief, overwork, and even other people. Personalities change. There's less sparkle, spontaneity, ambition, and interest in fewer and fewer things.

Bills may stack up unpaid, medications remain untaken. The person may be restless at night and may behave unsafely (eat spoiled food, become unable to understand the significance of a smoke-filled room). The victim may misuse words, ask questions over and over again.

At some point, the afflicted person may become unable to write or speak coherently, to understand most spoken or written language, or to recognize anyone, including himself in a mirror. The patient becomes unable to feed himself, to chew and swallow and, in time, becomes bedridden and incontinent. Eventually, he loses consciousness and is unable to survive without total care.

The duration of the disease depends upon age of onset, individual health status, support systems, and treatment of concurrent health problems. On the average it may last 7 to 9 years; it can last as long as 20 years, and rarely, even longer.

The Diagnosis of Alzheimer's Disease

Since there are many treatable conditions with symptoms similar to Alzheimer's, it is important to be sure of a diagnosis. How soon the search for a certain diagnosis begins often depends on how successfully the sufferer has compensated for growing deficiencies. Many relatives report finding their own names, addresses, and phone numbers written on dozens of scraps of paper, frantic attempts to grasp a lifeline as the current bears away the victim. Also, family and friends may help delay the confrontation with problems as

they, sometimes subconsciously, take over the tasks that the impaired person can no longer accomplish. Child/parent roles subtly change. The titles "Keeper-of-the-finances" and "Maker-of-the-important-decisions" one day may be found to have shifted.

At the moment, an absolutely positive diagnosis of Alzheimer's disease comes only from brain-tissue biopsy (a procedure involving some pain and risk of infection) or from autopsy. Virtually all patients with the disease have been so diagnosed after a thorough physical, neurological, and psychological examination.

Such an examination usually includes a verbal test of mental sharpness. Questions might include—"Who is the president of the United States? In what year were you born? Can you count backward by sevens from one hundred?" The patient's ability to answer these questions AND the language skill with which the answers are given are considered since a decline in the skillful use of language can be a strong indicator of a parallel loss of mental ability.

Once the degree of mental confusion is ascertained, further physiological and neurological tests rule out possibilities other than Alzheimer's. A diagnosis of Alzheimer's typically comes after all other possibilities have been ruled out.

Similarly, a discussion of what Alzheimer's is may best begin by explaining what it is NOT.

What Alzheimer's Is Not

- It is not "hardening of the arteries," the once-classic explanation of the symptoms of senile dementia ("senile" means old, "dementia" means deprived-of-mind and is a term used to describe the mental loss that results from a variety of diseases including Alzheimer's).
- It is not just the natural course of aging. As we age, we lose nerve cells in the brain, cells which do not regenerate (by about age two, we have all the nerve cells we're going to have). That some 60,000 Alzheimer's victims in America were diagnosed before age 60, and that most people remain vital and creative at advanced ages, hint that something other than normal aging accounts for Alzheimer's.
- Although symptoms can be similar, it is not brought on by alcoholism or blows to the head (as in punch-drunk-fighter syndrome) or tumors or overmedication (the latter a major problem for older people) or folic acid or vitamin B12 deficiency or endocrine or fluid or electrolyte imbalances, most of these being treatable, even reversible, conditions.
- Alzheimer's is not depression. Although Alzheimer's sufferers may well become depressed about their declining mental powers, psychiatric treatment doesn't cure the disease. Patients with symptoms similar to Alzheimer's, who suffer from depression, should be urged to seek help.
- It is not communicable.
- It is not, at least to date and unlike some of the other causes of dementia, curable, and researchers are not in agreement as to its cause.

Acceptance and Denial

"They feel something has been snatched from them," a woman attending her first Alzheimer's support group meeting said. Her parents had had every reason to expect their retirement years to be happy and secure. Her father had built a successful business and intended to sell it, but Alzheimer's was making him unable to handle the complex business dealings that would lead to a sale. His fumbling attempts to continue the business made it less marketable by the day.

The woman's mother refused to admit that there was a disease at work, and instead blamed her husband for his inability to function. She would scream at him, and he would look up and say, "You're not my wife. My wife has crow-black hair," as indeed she did, decades ago.

Acceptance of the grim truth can be as difficult as denial. Patricia McGannon told the *Boston Globe* that she had seen her husband cry only three times in all the years she knew him: When President Kennedy was shot; when their daughter was seriously burned; and when he, Donald McGannon, president and chairman of Westinghouse Radio and Cable, Inc., was told he had Alzheimer's. The McGannons' daughter, Patricia Jean Cowen said, "I feel about my father and the tragedy of the disease the way I feel about Beethoven going deaf. The thing that was greatest about him, his mind, he lost."

Emotional Devastation

To be a member of an Alzheimer's family is to taste a bitter stew of frustration and anger and guilt and embarrassment and grief.

The late Dr. Monica Blumenthal of the University of Pittsburgh School of Medicine said, "In many ways, dementia is like death. It is the death of the mind. Most family members who are close to the patient will go through some phase of mourning which is often more grievous than that produced by death itself."

"It is," said Bobbie Glaze, a Minnesota woman who endured her husband's disease for 15 years, "a funeral that never ends."

Chicago authors Elizabeth Gilman McNulty and Meryl S. Dann interviewed caregiving

families of older people debilitated by Alzheimer's and other illnesses, and selected a dozen of the stories they were told for their book, *The Dilemma of Caring* (Charles C. Thomas, Springfield, Ill., publisher). Here are a few of the voices in that book:

• A man talking eight years after placing his mother in a nursing home—"Sometimes when there is a real good soprano in the church choir, I choke up. You see, mother sang at weddings and funerals, and she always sang the "Star-Spangled Banner" at local events. So when I hear a really good soprano, I feel that I am witnessing the prolonged, living death of a person who was once one thing and who now is nothing. And in witnessing her living death, I end up being a weekly mourner. I sometimes resent that I can't go to church without crying."

• The daughter-in-law of an afflicted woman talked about the dark feelings she had had over years of caring for a person who, after all, "isn't even my mother"—"Every one of these people walking into that nursing home on Sunday afternoon is there out of guilt... They certainly don't look happy... I think to myself, 'I hope my kids never put me in one.'"

• A caregiver who had lost 40 pounds and whose hair had fallen out to such an extent that she had to wear a wig, went to her doctor who told her her problems were the result of stress and advised her to forget everything for an hour a day—"Now how can you forget an 85-year-old woman lying in bed calling, 'Flo, come here. Flo. Flo?' How can you forget that? How can you hear it and not go see what's wrong. Of course, there's never anything wrong, but how can you just sit and say, 'I'm gonna ignore you.'"

• A professional social worker was surprised at some of her emotions when she became caregiver to her mother—"There was a sort of gleeful maliciousness in some of

my reactions to her, particularly in terms of my being more competent than she was... All my life, my mother was 'in charge.' And I always had to struggle, somehow, to find my place in the sun. As bad as it was, there was something about this situation that, at times, I secretly relished."

• The same social worker reflected on the Alzheimer's child's nightmare—"Of course everytime I forget something—and I do forget—I think what's going to happen? I have visions of myself in my mother's condition. Maybe it's one of the reasons it's so painful to be with my mother. I see myself there. It's just overwhelming. It's times like that when I really do believe it would be nice if we could work out some system when, at a given point, a committee or somebody says, 'Here, drink this, Honey.' And that's the end of that."

Abilities Rise to the Surface

Somewhere in the thick stew of emotions that accompany Alzheimer's disease, however, sometimes coming to dominate, is love and the finding of an amazing ability to endure.

Here is a letter written to the *Chicago Tribune* after that paper ran a series on Alzheimer's disease. The letter came from a woman writing from her home in rural New Zealand:

"My husband has had Alzheimer's for 17 years. He is now a total invalid, unable to speak, feed himself, incontinent, unable to stand. I still have him at home and look after him by myself which means washing, feeding, getting him up into a chair by day and back into bed at night. I can do it all by myself. I live in a very isolated area and am not often tempted out at night, but I do have many friends and interests and these I am able to do and see at home. In fact, wild parties have been known to go on with my husband sleeping peacefully in his chair in the midst of all the fun and games, so it is not all gloom and doom. I shall keep him at home unless I have to give up at some time, but I feel that I have got so far that it will have to be really drastic for me to stop. I could not have done it at all without mechanical aids like the two hoists, one slung from a hook in the ceiling to get him out of bed and into his wheel chair and onto his commode and the other (a helicopter harness covered in sheepskin) fitted onto a strong stand on wheels to get him from a wheel chair into a comfortable Lazy Boy which tips right back and lays him flat if I need to change a catheter if it suddenly blocks. I would not have missed this experience. It would be nice if he could speak, but holding hands and being silent can also pass on a lot."

Alzheimer's Cost to the Nation

The thievery of Alzheimer's reaches beyond the minds of the victims and the hearts of their families to pick these people's pockets as well. Nursing home care costs currently average upwards of $20,000 a year per patient; at-home care, more than $11,000. These financial burdens are seldom lessened by government or private insurance. Totalling disease-related costs of all Alzheimer's families, the national result (excluding loss of productivity) is a staggering $39 billion.

Projections into the future are still more distressing. By the year 2030, when 22 percent of our population will be 65 or older, and assuming a 7 percent inflation rate (a low assumption given the history of inflation of health care costs), the national Alzheimer's bill will be $750 billion.

History of the Disease

Some 80 years ago, a woman in Tubingen, Germany died; and a disease was born. The woman had been suffering from depression, loss of memory, loss of the ability to reason, "progressive jealousy" as neuropathologist Alois Alzheimer would describe it at a meeting of the South West German Society of Neurologists in November 1906. Similar symptoms had been observed in other patients by doctors long before Alzheimer, and those symptoms always had been dismissed as a natural part of the aging process. This woman, however, had not been elderly, and was only 51 when it became obvious that something was wrong with her.

Upon her death four years later, Dr. Alzheimer decided to apply a newly available stain to a thin slice of her brain taken at autopsy. Through his microscope, and the use of this special silver stain, he was able to see two abnormal structures, i.e., neurofibrillary tangles, and neuritic plaques, both hallmarks of the disease that now bears his name.

Although the disease carries his name, Dr. Alzheimer made a mistake that would cloud understanding of Alzheimer's disease for scores of years. He thought that, because the pathology he saw in the brain of someone relatively young at onset of symptoms, he was seeing something different from what was going on in older people with similar symptoms. A division was supposed between "pre-senility" (a disease) and the natural effects of aging, "senility."

More than half a century later, a group of British researchers examined brains of relatively young, deceased dementia sufferers and compared what they saw to those of elderly, deceased dementia sufferers. What they saw was one and the same—Alzheimer's disease. (With Alzheimer's, as with some other diseases, the earlier in life one shows symptoms, the more virulent the course of the disease is likely to be. Thus distinctions often are made between early-onset—before about age 65—and other—after age 65—cases of the disease. Some researchers push the dividing line back to age 75 or even 79. There also is evidence that early-onset Alzheimer's is associated with a greater risk of the disease attacking close blood relatives.)

Recognizing Alzheimer's disease as an illness is all important. There may be nothing to gain in fighting Mother Nature, but if it's not natural aging but disease that is the thief of minds, there may be everything to lose by declining the fight. According to Dr. Michael Shelanski of the New York University Medical school: "The failure (to view brain pathology as an illness) will turn victories in our crusades against cancer and heart disease into hollow shells, and the fruits of these victories will be bitter ones as we watch the wards of our hospitals fill with older people who have strong bodies but diminished minds."

A Silent Epidemic

Even after it was clear to much of the medical community that Alzheimer's was a disease, other factors conspired to keep this ailment almost unknown by the general public even though it was widespread among them:

The disease primarily affected the elderly. There could be no appealing "poster child" for Alzheimer's.

It affected the brain. The supposed stigma of a "mental" problem in the family often kept victims hidden away out of sight and undiagnosed.

No sufferers with famous names drew public attention.

Only a few years ago, Jerome H. Stone, president of the Alzheimer's Disease and Related Disorders Association (ADRDA), termed the disease "A silent epidemic."

It is silent no longer.

As the percentage of America's over-65 population has grown and become a major influence group, interest in the problems of older people—including Alzheimer's disease—has grown. Rita Hayworth is known to be a sufferer as was artist Norman Rockwell, mystery writer Ross McDonald, actors Arthur O'Connell and Edmund O'Brien, and many other "names." The disease now has been featured on the cover of *Newsweek*, discussed by television talk-show hosts Phil Donahue, David Susskind, and others; portrayed in documentaries, become the focus of books; dramatized in the Emmy-award winning television special "Do You Remember Love?" There is a national Alzheimer's Awareness month (November) and even Alzheimer's golf tournaments.

The Drawback of Becoming a Well-known Disease

After years of neglect, Alzheimer's disease is finally recognized for the deadly, devastat-

ing disease it is. With that recognition have come some problems.

In the past, a doctor, sometimes unsure of the cause of demented behavior in an older person, would label the patient "senile," which merely means "old." If not labeled senile, the diagnosis became "hardening of the arteries." A diagnosis of Alzheimer's was rare. Now, however, the disease is mentioned in the media daily, appears in each new medical journal, is on the lips of even the average layperson, and now it has become the latest "wastebasket" diagnosis.

Although the number of persons who are misdiagnosed as Alzheimer's patients when they in fact have a treatable dementia is probably small, many Alzheimer's patients have other, treatable health problems in addition to Alzheimer's, and tending to these problems can improve their condition overall.

The other major drawback to the recently spotlighted disease is a rash of bogus "cures," "treatments," and "medications." The problem has prompted the following warning printed by ADRDA in its newsletter:

"Several regimens, treatments, food substances, and drugs have been advertised as 'cures,' 'treatments,' and 'retardants' for Alzheimer's disease. Some may have questionable value. Says Dr. Robert Katzman, chairman of the Alzheimer's Disease and Related Disorders Association's (ADRDA) Medical and Scientific Advisory board, 'The fact is that at this moment we don't know of any drug or any other treatment that stops the progression of Alzheimer's disease.' Skepticism can be very healthy. Before embarking on any program or any course of treatment, it would be wise to check with your family physician, ADRDA chapter, local medical school, or perhaps, when in doubt, the Food and Drug Administration. You can then make an informed decision."

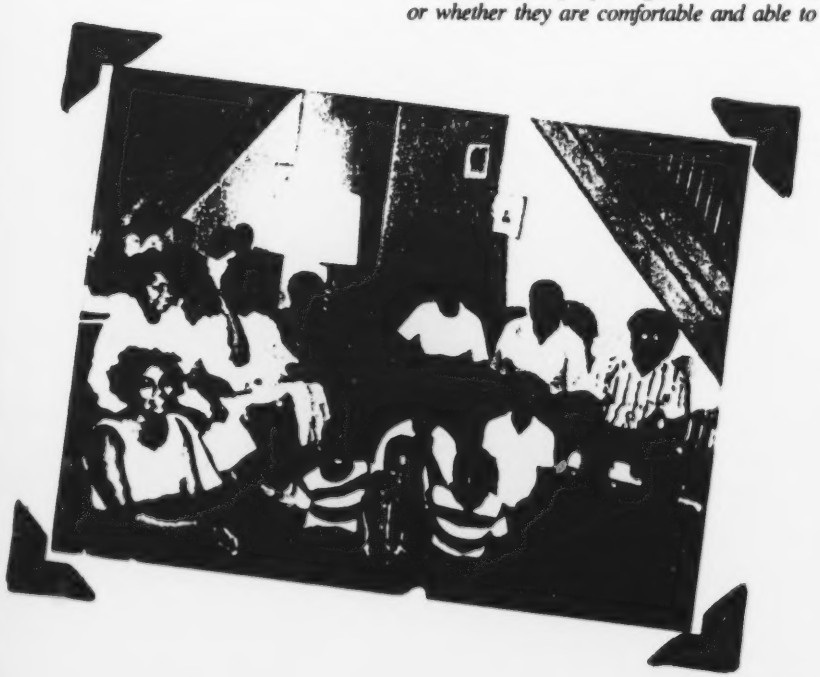
A 1984 *Modern Maturity* magazine article focused on two "treatments" and warned against "quack cures" which "have been preying on families of Alzheimer's patients. Chelation therapy flushes aluminum from the systems of Alzheimer's sufferers under the theory that the mineral is the cause of the disease's pathology. "In desperation, families pay $5,000 to $8,000 for a series of treatments with chelating agents that scientists say undoubtedly remove some aluminum. But there is no proof that it helps the patient... The second 'treatment' is blue-green algae, which has been aggressively advertised. 'Not only is it not proven effective for Alzheimer's disease,' explains (Dr. Robert) Katzman, 'but its safety is questionable and has led to seizure by the Food and Drug Administration.'"

TREATMENT AND CAREGIVING ISSUES

Alzheimer's Disease: Treatment

Despite many promising research projects, there is, at this writing, no medically accepted treatment available to Alzheimer's patients that reverses or even halts the neurological damage of the disease. Although the disease cannot be treated, the patient can. Problems that go hand-in-hand with Alzheimer's disease—improper nutrition, incontinence, wandering, unsafe behavior (forgetting to turn off an iron, for example)—all can be managed. With proper care, an Alzheimer's sufferer need not be stripped of all comfort and dignity.

In a 1985 speech, Nancy Mace, a writer and researcher on Alzheimer's and related subjects, said, *"Clearly, for some patients, some of the time, having a dementia is not synonymous with suffering. We (caregivers and health care professionals) can make a difference in whether such people suffer with their illness or whether they are comfortable and able to enjoy moment-to-moment. These success stories are rare. They are far outnumbered by stories of patient suffering and family suffering. I believe that our charge for the coming decade is to learn what we can do to rehabilitate patients, to enable them to live WITH their illness, to improve their function, to remove excess disability, and to improve their quality of life."*



A Support Team

Planning ahead—difficult as it is in the press of keeping up with the current needs of the patient, difficult as it is to face the even greater dysfunction and even greater demands of the future—is vital. The time to screen nursing homes—since the best ones usually have waiting lists—is well before the patient will need such care. Likewise, the time to have the patient's will drawn is before the person loses the competency to make bequests.

Early in the course of the disease, a caregiver probably will want to assemble a support team consisting of a doctor or group of specialists, of course, emergency or respite caregivers (family, friends and also professionals) and a lawyer.

A Lawyer for Alzheimer's Disease?

Charles Bell, a Pittsburgh attorney with both personal and professional experience with Alzheimer's, cautions, "Families frequently do not realize that the affliction of Alzheimer's disease engenders many legal problems affecting the patient and family until it is too late to solve them appropriately. The first step the patient and family should take immediately after diagnosis is a consultation with a knowledgeable attorney to plan for the expected legal and financial complications."

Names of lawyers in your area can be obtained through state bar associations. Ideally, Alzheimer's families would want a lawyer experienced in matters such as guardianship, financial responsibility of children

to the parent, and legal rights when placing a patient in a nursing home. In short, all the complex—and changing—issues that may arise as the years of care pass may require legal advice. Keep in mind that state laws vary and are subject to change.

Legal Issues

• A will: Everyone should have a will. But, since many people put off the task of writing one, it is not surprising that people who eventually become Alzheimer's victims do likewise. Because a certain level of mental competency is necessary in order to legally make bequests, if the issue is to be addressed, it must be drawn early in the course of the disease.

• Gift: The easiest way to transfer assets from one person to another is through an outright gift from the patient to a spouse or child. Drawbacks to an outright gift include any taxes that the spouse or child would have to pay on the earnings of the gift, the lack of constraints on the spouse or child in the use of the assets, and the possible unwillingness of an Alzheimer's patient, perhaps unusually suspicious and fearful because of the disease, to make such a gift.

• Power of attorney: This is a legal document drawn up on behalf of the patient giving the authority to manage his financial affairs to a spouse, adult child, or other competent person. A durable power of attorney states that the power conferred will survive disability in the person granting the power. The power of attorney is easily drawn and revocable at any time. Some banks or insurance companies, however, may require that separate power-of-attorney documents be drawn specifically for them.

• Conservatorship: Sometimes called a "guardianship of property," this is a means of securing the right to manage another's financial affairs after that person has become unable to manage them. It can be a means by which an Alzheimer's patient just beginning to lose thinking abilities gives over his financial affairs to another person or to a financial institution. A lawyer must file a conservatorship petition in court. A hearing is held, and a judge decides on the merits of the petition. This process can be costly in terms of legal fees and can take several months. The conservator, once appointed by the judge, must file periodic financial reports with the court.

• Guardianship of person: Similar to a conservatorship, this form of guardianship would be used not to manage assets but to manage the physical care of the patient who might be refusing to submit to such care. Guardianship of person is more difficult to obtain than guardianship of property and is usually requested when there is no spouse or family member to care for the patient.

• Trusts: For larger estates—more than about $100,000—a trust can have tax and

probate advantages. Legal fees and the acceptance of administrative duties are involved in setting up a trust.

In general, the caregiver's own mortality should be kept in mind, and provisions for continuing patient care should be made in case the caregiver is struck by death or disability.

The above are far from all the legal questions that can arise with an Alzheimer's patient. Some others will be dealt with later. It must be kept in mind that laws vary from state to state and are subject to change. It is important to see an attorney to discuss these issues and adequately plan for the future.

The Alzheimer's Disease and Related Disorders Association (ADRDA)

An important member of an Alzheimer's support team is the national organization that has been established to fight the disease, to assist caregivers, and to inform the public. The growth of ADRDA, not coincidentally, has paralleled the growth of interest and concern over the disease.

Bobbie Glaze, a few years ago a housewife in Watertown, South Dakota, finds herself attending meetings with Yasmin Aga Kahn, daughter of Ali Kahn and Rita Hayworth. The widely different worlds of the two women are bridged by Alzheimer's disease.

Glaze spent the early 1970s trying to find a doctor who could put a name to the disease that was causing her husband's precipitous loss of memory, erosion of personality, and erratic behavior. Even when she had a word, Alzheimer's, "It was two years before I could find anyone who could spell it." Toward the end of that decade she and a few other Alzheimer's families in the Minneapolis area (where she had moved) discovered each other's existence and founded a support group.

The same thing was happening elsewhere and in 1979, a handful of such groups joined together to form the Alzheimer's Disease and Related Disorders Association, and Jerome H. Stone of the Chicago-based Stone Container Corporation was chosen president.

This privately funded and volunteer-based organization today has more than 140 chapters and affiliates and more than 1,000 support groups in 44 states and the District of Columbia. It has a mailing list of more than 400,000 names (members, medical people, journalists, etc.). A much newer international organization is just beginning to take shape.

The Association's mission is expressed and served through its goals of family support, education, public awareness and research.

The Association's research budget has grown from $78,000 in 1982 to a projected $1.5 million in 1986. That $2 million figure, however, is only about a tenth of the amount of money raised annually for multiple sclerosis, a terrible disease but one which affects only about a tenth of the number of people afflicted with Alzheimer's.

The Association has "and Related Disorders" affixed to its name because there are other dementing diseases including Creutzfeldt-Jakob disease and Pick's disease which follow a path nearly indistinguishable from Alzheimer's, whose victims require the same care, and whose families desperately need the same support. Although the pathology of the diseases may differ somewhat, everything said in this booklet pertaining to care, financial burdens, and emotional stress on families applies as much to these related disorders as it does to Alzheimer's.

The address of the Alzheimer's Disease and Related Disorders Association, Inc., is:

70 E. Lake Street
Suite 600
Chicago, Illinois 60601

The office phone number there is:
(312) 853-3060.

To find the ADRDA chapter nearest you or for advice on where to turn for services, there is a toll-free number:
(800) 621-0379.

In Illinois, the toll-free number is:
(800) 572-6037.

Caregiving

Care of an Alzheimer's patient can last two decades, a generation. It can entail virtually 24 hours a day supervision for all that time, an unrelenting onslaught. The job can be as thankless as it is demanding. In early stages, the patient does not look "sick." Friends and relatives who do not see the patient on "bad" days do not see the burden the caregiver shoulders.

In the book *The Dilemma of Caring*, a woman talks about her mother, an Alzheimer's victim who did not appear to be a victim:

"Those that would see her out on the street in her $400 suit, with her beautiful hair, couldn't believe that she was as bad off as she was. Mother would put up a facade that could hold for a few social minutes, but people didn't realize that...The neighbors and others who didn't know her that well would think, 'She's terrific. She's fine. What's the matter with her daughter?' One of Mother's sisters who visited here couldn't believe there was something the matter with her. 'Oh, she's just a little forgetful; aren't we all?' At the time, she was wetting the bed."

Anthony Brandt in his "Ethics" column in *Esquire* magazine, wrote of how his mother dealt with Alzheimer's in her mother:

"My mother took her into our home, fed her, bathed her, changed the sheets when she fouled them, calmed her down when she hallucinated and screamed at the air and tore off her nightgown, kept her and nursed her for six months, until, half dead with exhaustion, miserable with guilt, she put her in a nursing home where she finally died. Then the relatives, the same ones who didn't once come to see my grandmother when she was in our house, never visited her in the nursing home, and had no idea what the old woman had become, turned on my mother and critized her viciously for 'putting her away.' Her own mother. So she had to deal with that too, and she never forgave them."

"Our friends soon stopped calling," an Arizona man whose wife is an Alzheimer's victim said. "You just get cut off from the community, isolated."

For caregivers determined not to be isolated by their loved one's disease, there are difficult questions to answer: "How free am I to establish relationships, perhaps intimate relationships?" "How do I deal with my decision?"

Aware of possible genetic components of the disease, caregivers, weary and overburdened, may well forget something and suddenly wonder in terror, "Am I getting it?"

Fear, guilt, shame, denial, worry, disgust, anger, frustration—any caregiver can reel off the devastating emotions that are part of caring for a loved one who may well come to be, as one woman caregiver put it, "a shell that breathes."

Anyone who sees what Alzheimer's does to families must wonder: "Who is the true victim of this disease; the patient or the caregiver?"

At-home Care

An Alzheimer's patient usually is cared for at home in the beginning.

About two-thirds of all Alzheimer's sufferers are being cared for at home. For the patient, this can mean the security of familiar surroundings and familiar faces. Costs, at least initially, tend to be lower at home than they are in a nursing home, although caregivers with the means to do so have turned parts of their homes into near-hospitals. While there are rewards in knowing that the patient is getting loving care at home and that everything possible is being done for the patient's comfort, days can be horribly trying and long. One caregiver thought about his day-after-day of feeding, bathing, making sure the patient was not doing anything unsafe, and dealing with wanderings at all hours of the night and came up with a name for those days—"the 36-hour day."

That is the name of the most comprehensive and practical Alzheimer's disease caregivers' manual. *The 36-Hour Day* by Nancy L. Mace

and Peter V. Rabins, M.D. contains chapters covering everything from "When a Person Must Give Up a Job" to "Dying at Home." It discusses patient seizures, delusions, incontinence, night wandering, and inappropriate sexual behavior. It deals with the caregiver's anger, fatigue, isolation, need for help, and more. Advice ranges from areas as seemingly simple and mundane as non-slip decals in the bottom of the tub to those as complex as the feelings of the caregiver's young children toward the Alzheimer's victim.

For many caregivers, there comes a time when, despite their best efforts, despite their 36-hour days, they cannot carry the burden anymore without help that goes beyond advice found in a book or in a support group. Not long ago, the only alternative for someone at such a crossroads was the nursing home. Now, however, there are interim possibilities to consider. (Day care, for instance, may be available to such patients though not advertised that way.)

In-home Respite Care

This is perhaps the most traditional means of giving the primary caregiver a little "breather." In-home care brings a caregiving helper into the home for a few hours, for a weekend, or for a week or more at a time. There is no travel trauma for the patient, no new surroundings. The primary caregiver retains control over decisions affecting the care of the patient. Respite care can come from a variety of sources, some paid, some volunteer. Here is a sampling of some of the options:

- Friends or family members are likely the first to be called upon to lend a hand.
- Volunteers who are trained by a sponsoring agency or religious organization, are provided free of charge.
- Cooperatives are an organized group of caregivers that help each other out, usually trading time for time.
- Paid professionals have varying skill levels. A companion/homemaker sensitive to the needs of Alzheimer's victims could occupy their time and perhaps prepare meals. The next level is home-health aide or nurse's aide, trained in personal care; for example, bathing, assisting with going to the bathroom. A registered nurse or licensed practical nurse would be needed to provide skilled care to a more physically ill patient and generally would be ordered by a physician. For-profit providers of such care generally charge an hourly rate of from $5 to $25 depending on the skill level provided, while not-for-profit agencies usually tailor their rates to the financial resources of the client.

Local health departments, an office on aging, a community social worker, or the nearest ADRDA chapter (a listing of local chapters is available by calling or writing the national Association) should be able to advise on the availability of at-home respite care in your area.

If there is no such care available, and you would like to help in setting up a program, the national Alzheimer's Disease and Related Disorders Association office can suggest where model programs have operated and have dealt successfully with problems of publicity, training, logistics, and setting fees.

Out-of-the-home Respite Care

While out-of-home respite care may be appropriate for some patients, this is a relatively new concept and there is great variability from place to place in the availability, quality and cost. Following is a sampling of some options:

- Day care—In community centers, religious organizations, retirement homes, nursing homes, hospitals, some staffed by volunteers, some by paid personnel.
- Short-term institutionalization—Unused beds in some retirement homes, hospitals, and nursing homes are available for Alzheimer's patients. Costs run about $50 to $75 a day. Some facilities have a required minimum stay, and some accept only those Alzheimer's patients who are not combative, incontinent, or wanderers.
- Foster care—Care provided in a small, personal setting, often the home of an individual or couple licensed through a social service agency.
- Bed and board—Similar to a boarding house, room and food are provided in a residence, the food either cooked for the individual or cooked by the individual in a communal kitchen or personal kitchenette. Bed and board homes would be suitable only for a very early-stage Alzheimer's patient.
- Bed and care—similar to a bed and board home but with a certain amount of non-skilled, personal care provided. In some states, such living arrangements must be licensed and meals must meet standards.
- Vacations—Leaving the patient behind in some sort of facility or taking him or her may be an extremely stressful time for all. "Resort-like" vacation packages tailored for Alzheimer's caregivers and their patients are emerging as an option. Activities are planned for both or for each individually.

Nursing Homes

For most caregivers whose patients have survived into the later stages of the disease, the nursing home may be the only option. Within the category, "nursing home," however, there are some alternatives. There are religiously affiliated, usually not-for-profit, homes and there are homes run for a profit. There are homes in which a wide range of disabilities are represented and homes with designated Alzheimer's units. There are nursing homes run on a pay-as-you-go basis and life care facilities which require an up-front payment (sometimes the patient's

life savings) and may then provide care for life even after the patient's funds are exhausted. The decision to place a loved one in a nursing home is a terribly difficult one. Once that decision is made, another important decision to be faced is which home?

How to Choose a Nursing Home

Visit several homes to give some basis for comparison. Visit before placement is necessary (because there often are waiting lists and because you do not want to be rushed while making such an important decision). Visit when you can spend enough time to thoroughly check the facilities. *The 36-Hour Day* contains a lengthy checklist of things to look for ranging from licensing to the availability of snacks.

In general, you will want to be assured of cleanliness, safety (fire alarms, fire doors, sprinkler systems, evacuation plans), medication policies, costs and what they cover, extra costs (laundry, phone, transportation, etc.), visiting hours and procedures, conditions under which a patient might be asked to leave (difficult behavior, perhaps or when his money runs out and he must go on Public Assistance). Ask to see a sample placement contract; and if there is anything you do not understand, consult a lawyer. Medicaid regulations vary from state to state, and you will want to know, for example, if you can be held legally responsible for the expenses of the patient.

Special Considerations in Placing an Alzheimer Patient

Because Alzheimer's is a progressively degenerating disease, a view to the future is necessary in considering possible homes. Does the facility have varying levels of care so that, when the time comes that more intensive degree of care is needed, the patient will not have to go through another admittance procedure, will not have to go through the trauma of a move? Is it really important that the home has a lovely library when the patient is losing the ability to read?

As recognition of the disease grows, there are a growing number of nursing homes offering specialized care for Alzheimer's patients often in a separate wing or floor of the home. This is not necessarily a good thing. If you are considering a nursing home with a separate area for this purpose, beware it is not used as a dumping ground for the often troublesome Alzheimer's patients who are not confined to beds, do not follow directions easily, or do not keep usual schedules. If, however, separation of the Alzheimer's sufferers is done to deal more effectively with them rather than to avoid dealing with them, the results can be laudatory.

A Segregated Alzheimer's Nursing Home

Carly Hellen is the Alzheimer's program director at the Bethany Terrace nursing home in Morton Grove, Illinois, a home that has decided to segregate its Alzheimer's residents. Her experiences are worth recounting here as a positive approach to Alzheimer's-patient care.

"We focus on companionship and supervision in a safe, therapeutic environment. The bottom line is programming and environment. We have specific training for the staff to deal with Alzheimer's behavior; anxiety, non-verbal language, reversal of day/night schedule, etc. That training is for anyone who comes in contact with the patient, not just the nursing staff

but the housekeeping, maintenance and dietary staffs as well.

"We plan activities for seven days a week. Nurses' aides take over when the activity staff is not there. Another important consideration is weight and nutrition monitoring. Non-eating can be a serious problem. We weigh everyone once a week.

"There is an emphasis on mobility here and a deemphasis on the use of restraints and drugs. We find that when the patients lose mobility, they deteriorate greatly. Also, if they don't walk for a time, they cannot relearn walking, so if any of our patients go, for instance, to the hospital for a while, I make sure that, if possible, they don't just lie in bed there. We encourage patients to do as much as possible for themselves, to retain as normal a life as they can in a stress-free environment. We adapt to their needs rather than trying to press them into our environment.

"It's important to keep the patients' families involved in their care. We have family support meetings once a month, a chance to ventilate feelings and concerns. We also are concerned about support for the staff. We encourage the staff to deal intensely with the patients here but not to take the patients home in their minds because that's when burnout happens."

The Financial Burden

Much of the mail that pours into the ADRDA national headquarters in Chicago concerns the high cost of nursing home care, currently averaging something more than $2,000/month. Here are excerpts form some of the letters:

"My father was recently admitted to a nursing home. He is 85 years old and his mind is nearly gone. The doctors say it is Alzheimer's disease. The charge at the nursing home is $50 a day. My mother is 77 years old and healthy. They saved and sacrificed all their lives and now their saving is vanishing fast. It seems so unfair that she should lose her husband intellectually and then lose all her money as well."—O.F., Wisconsin.

"My husband is 70 and in a rest home, and it's costing me a fortune. Our savings are going down fast, hardearned money, farmers in Depression years, sweat of our brow. Please help stop costs. Help, help. No insurance, only Medicare and that does not pay medications or rest homes. What will I live on?"—L.L., Vermont.

"Do you know someone in Congress to whom my friend (a caregiver) can write and ask for 'help?' She has tried in every way to get her husband in a Veterans Administration nursing home but has been told at every turn that there is a long waiting list. This man is in diapers, lost all his self-help skills, cannot feed himself in any human fashion, cannot pour a drink of water for himself, cannot call for help, speech is almost completely gone. This lady has tried her very best to care for her husband at home, but this is an impossible situation. The nursing home staff tell her there is no way she can return him to her home and care for him alone. She says her only alternative (because of the high cost of private professional care) is to take him back home, seal up the windows and doors and live as long as they can."—O.T., Georgia.

WHERE TO TURN FOR FINANCIAL HELP

Medicare

Medicare is a federal program intended as a government health insurance plan for older Americans. For the most part, Medicare is of little benefit for long-term care services for the Alzheimer's patient.

To qualify for Medicare benefits (applications for coverage can be made through Social Security offices), the patient must enter a nursing home following a stay in the hospital. Unless there is a health problem requiring hospitalization in addition to Alzheimer's disease, this condition is unlikely to be met. Another condition is that the patient is placed in the nursing home to be treated or rehabilitated as a result of the same disease which required hospitalization. An Alzheimer's patient may not meet this condition. Another requirement is that the patient require "skilled" nursing care by a registered nurse or licensed practical nurse, or must be a candidate for rehabilitation therapy. Since there currently is no rehabilitation for Alzheimer's sufferers, and since in the earlier stages of the disease, patients need "custodial" care (assistance in bathing, eating, occupying time, etc.) rather than "skilled" care (injection of drugs, monitoring an IV, catheterization, etc.), these patients again fail to meet Medicare's requirements, and are denied benefits.

For additional information about Medicare, contact the nearest Social Security office. A handbook on Medicare is available. To get a copy, write:

"Your Medicare Handbook"
U.S. Government Printing Office
Washington, DC 20402.

Medicaid

Like Medicare, Medicaid is a federal program, but; unlike Medicare, it is administered by individual states. The administering agency differs from state to state, as well. It may be the department of welfare, the department of social services, or the health department.

As the administering department changes from state to state, so too do the laws covering the conditions of Medicaid assistance. One thing remains constant, the regulations are confusing, changing, and unlikely to please those who apply.

Medicaid is intended to assist those who have exhausted their own funds in paying for their health care. It is not intended to preserve the savings of individuals or families. Consequently, only when the person has exhausted all savings and exists at or below the poverty level, does he or she qualify for coverage.

Private Insurance

Historically, private insurance has not been much help in paying the costs of long term, as opposed to acute care. Fortunately, this may well be changing as the nature of Alzheimer's disease, and the needs of those who bear the burden of the disease, become better recognized.

Some private companies are beginning to offer limited nursing home insurance policies, what one industry official told *U.S. News and World Report* is "the last great uninsured risk of the elderly." Aetna, Metropolitan Life, Firemen's Fund, United Equitable, and Prudential are a few of the companies that have entered this market.

Coverage varies greatly. Some of these policies currently exclude Alzheimer's disease. As with all insurance policies, read the policy carefully. Most policies pay a fixed amount per day, about $40 to $70, but some allow the purchaser to pick the level of coverage within that range. Some policies cover for only one year, others for several. Annual costs of such coverages range from about $600 to about $1,800 for a person in his or her late 60s.

Veterans Administration System

For information on the possibility of placing a veteran with Alzheimer's disease in a VA facility, contact your nearest Veterans Administration office or write:

Veterans Administration
Washington, DC 20402.

Dr. Paul Haber, then the VA's chief medical officer for extended care, told the *Chicago Tribune* in 1981 that Alzheimer's disease is "very labor intensive. The Alzheimer's patient is sometimes quarrelsome, self-destructive, wanders, is disoriented. If we admitted all the Alzheimer's veterans, our resources would soon be depleted."

In attempting to not deplete all its resources on Alzheimer's patients, the VA has regulated the flow of these patients into its facilities. Although the VA has designated six centers as Geriatric Research Education and Clinical centers (in America Lake, WA; Bronx, NY; Bedford, MA; Sepulvada, CA; and Minneapolis, MN), they are not specialists in Alzheimer's disease.

The ADRDA statement of a "National Program to Conquer Alzheimer's Disease" says this about the VA:

"The Veterans Administration currently has no consistent policy with respect to veterans with Alzheimer's disease. This has resulted in uneven, some believe unfair, treatment of veterans. Some victims of the disease are admitted to VA medical facilities, while others are denied admission or referred to other state or private agencies. In some instances, veterans are being forced to leave VA facilities or are being 'outplaced,' thereby distrupting their care and placing even greater strain on the family.

"The problem threatens to become even more serious as far greater numbers of veterans enter the vulnerable over-65 age bracket...By 1995, that segment of the population will grow to over 8 million."

Social Security Disability

Another area of possible financial support for Alzheimer's victims which the ADRDA has found to be wanting is the Social Security Disability program and the Supplemental Security Income program, both administered by the Social Security Administration.

The first of these programs is intended to aid disabled workers who have contributed to the Social Security Trust Fund through the income tax deductions. The second provides for a minimum income level for those aged, blind, and disabled persons who qualify because of financial need.

Under both programs, the definition of disability is "an inability to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment which can be expected to end in death or has lasted or can be expected to last for a continuous period of not less than 12 months." A special disability determination unit in each state determines whether or not an applicant is legally disabled.

Here is what the ADRDA Program to Conquer Alzheimer's Disease says about these two programs:

"The guidelines used by claims examiners to determine eligibility are somewhat vague when it comes to Alzheimer's disease and related disorders...The disease is not listed among those brain disorders specifically identified in the guidelines. At the present time, a determination of disability due to Alzheimer's disease must be made under the 'mental disorders' category. Unfortunately, the eligibility criteria under this category do not lend themselves to cases involving Alzheimer's disease. Furthermore, in some areas, state laws prohibit the use of certain specific diagnostic tools needed to demonstrate deterioration in intellectual functioning."

The ADRDA Program notes a typical example in which a 58-year-old woman, diagnosed as having Alzheimer's, was denied benefits even though the Social Security Administration affirmed to her that she has "some difficulty in concentrating and remembering and an inability to travel by yourself."

In light of the above, an Alzheimer's caregiver must pursue these benefits aggressively. One tool that has proven helpful in supporting claims of an inability to work is a day-to-day log of the patient's functional abilities. The ADRDA Chapters can provide disability documentation kits to those in need of them.

RESEARCH IN ALZHEIMER'S DISEASE

Theories as to the cause of this horrible, as-yet incurable illness which wastes its victims and wounds their families range all over the medical map. All over that same map, however, researchers are probing ever deeper into the secrets of the disease.

Is Alzheimer's a Chemical Deficiency?

Among some 25 brain chemicals that aid in transmitting messages from one nerve cell to another is acetylcholine. The brains of older people who are free of Alzheimer's contain less of this chemical than do the brains of younger people. But an Alzheimer's brain can suffer the loss of as much as 90 percent of acetylcholine.

It would seem logical that administering acetylcholine or its dietary relative, lecithin, would alleviate the symptoms of Alzheimer's disease as the drug L-dopa has alleviated the symptoms of Parkinsonism.

Tests of long-term ingestion of lecithin, however, have so far shown only minimal, qualified success.

Does a Virus Cause Alzheimer's?

We know that Alzheimer's is not a communicable disease, and—contrary to ordinary infections—is not accompanied by a fever or an elevated white-cell count. If this disease is caused by a virus, that virus would have to be an unusual one, not the sort that causes the common cold or the flu. There are other diseases that seem to be caused by an unusual, so-called "slow virus" or perhaps by an even stranger villain.

Reseachers at the University of California at San Francisco have isolated (after a decade of attempts) a submicroscopic infectious particle, a "prion" which seems quite similar to the material which makes up the plaques found in Alzheimer's brains. If Alzheimer's is caused by such an agent, the disease should be transmissible, but attempts to transmit it have not worked. An infectious agent at work in Alzheimer's disease therefore is neither proven nor rejected.

Is Alzheimer's the Result of a Genetic Abnormality?

Dr. Leonard L. Heston, professor of psychiatry at the University of Minnesota Medical School, is one of the main researchers in this field. Dr. Heston has said that, "The risks (of developing Alzheimer's) are not really large compared to many others inherent in life." He thinks, however, that the disease carries a "familial" component that seems to pose a statistically significant threat to the children and siblings of the victims of this sort of Alzheimer's. The families at risk are, he has written, "Families with relatively severe disease, and among the most straightforward ways of identifying such families are age at onset and proportion of relatives affected."

A person who has several close family members whose symptoms appeared before age 65 is at a much higher risk of developing Alzheimer's than is a member of the general public. Heston, however, cautions that not even an individual at greater risk necessarily gets the disease.

Is Alzheimer's Caused by the Toxic Effects of Aluminum?

In 1965, researchers were able to produce neurofibrillary tangles (one of the hallmark pathologies of Alzheimer's) in the brains of laboratory animals by injecting aluminum salts. There are other indications of a link between aluminum and Alzheimer's. Chemicals that flush aluminum from the brain in a process called "chelation" have been experimented with, but these experiments have proven inconclusive. Research now focuses more on elevated aluminum levels as a symptom rather than a cause of the disease.

Is Alzheimer's the Result of a Malfunction of the Body's Disease Defense System?

Dr. Barry Arnason, chairman of the neurology department at the University of Chicago Pritzker School of Medicine, noted that, in dementia, "Selected nerve cells die and that affects memory. There are several other diseases in which selected nerve cells die and in one of them, patients develop antibodies against certain nerve cells. It is believed that there then is an immunologic attack against those nerve cells. That seems to raise the possibility that the selected death of nerve cells in Alzheimer's disease is due to immunological reasons."

Seeing the Whole "Animal"

If the search for the cause of Alzheimer's disease were not complicated enough, consider that many researchers are beginning to believe that Alzheimer's disease may well be caused by a combination of some, or even many, of these possibilities.

Richard J. Wurtman, professor of neuroendocrine regulation at Massachusetts Institute of Technology, writing in the magazine, *Scientific American*, said of investigators who focus on just one causal path to Alzheimer's, *"Just so did the six blind men conclude that an elephant was very much like a wall, spear, snake, tree, fan or rope— depending on which part they happened to touch. The elephant was all of these, but they had not perceived its essential elephantness. Not many years ago, different investigators assumed, at least for the purpose of investigation, that cancer is caused by viruses, foods, faulty genes or impaired regulation of genes, environmental toxins, radiation, or immune system deficiencies. All the investigators turned out to be correct; now they are converging on what may be the essential 'elephantness' of cancer. In time, the same thing may happen for Alzheimer's disease."*

Funding Research

In 1985, the federal government, the major funding source for Alzheimer's-related research, committed more than $50 million to attempt to broaden knowledge of this disease. More than half of the funding came from the National Institute on Aging, one of the National Insitutes of Health. In October 1984, the Institute on Aging announced the establishment of five Alzheimer's Disease Research centers and the granting of $3.5 million for the first year of operation. In October of 1985, the Institute on Aging announced five more centers and awarded $3.4 million for their first year of operation and a total of $25 million over the next 5 years.

Other research monies came from private foundations including the ADRDA which gave $694,000 in 1985. This amount was nearly 20 times the amount it allocated to research in 1982, the first year the association made such grants. The National Retired Teachers Association (NRTA) instituted an educational and fund-raising program for Alzheimer's disease. Funds raised went to the National Institute on Aging for direct research and partial underwriting of a technical workshop on diagnosing Alzheimer's.

Alzheimer's research monies go to support investigations ranging from looking into basic molecular structure to helping families better cope with a victim, from maintaining brain tissue banks to the developing of simpler, surer diagnostic techniques.

How You Can Aid the Research on Alzheimer's Disease

Anyone can support research through contributions made to ADRDA, to AARP Andrus Foundation, or made directly to universities undertaking this type of research with the stipulation that the funds be used for Alzheimer's-related research. Families of Alzheimer's victims can aid in further ways,

by answering research questionnaires and by requesting that an autopsy be performed after that patient's death.

Autopsy

For many families, the autopsy decision is terribly difficult. Religious belief may not condone the procedure. There may be fears (unfounded fears, doctors say) of disfigurement of the body or disrespectful handling of tissue. There may be a sense that, since the patient is now beyond help, there is no need to disturb even the remains of someone who, finally, is at peace.

The reasons for autopsy are, first, the family needs a confirmation or denial of Alzheimer's disease. Second, there is a need for brain tissue which is essential for many research programs. Researchers need such samples in that there are no animal models of Alzheimer's disease, no fly or cat or monkey that can yield a brain showing the pathology of Alzheimer's. As neurologist John Morris at Washington University's Memory and Aging project put it, "Alzheimer's disease is a uniquely human disorder. It affects exactly those things that make us human."

Autopsy can be planned far in advance. It is much wiser to do so than to wait until the emotion-filled time at the death of the patient. For research purposes in some cases, it is necessary that the brain be autopsied within a very short time after death . . . If prior arrangements have not been made, such research may not be possible. ADRDA's toll-free number is 800-621-0379, or 800-572-6037 in Illinois, for more information. After an autopsy has been performed, autopsy results are usually available in about three to six months.

There may be some expenses associated with the autopsy. Some researchers in need of tissue samples, do not charge for removal, transportation or examination of tissue. This may not always be the case.

Public Awareness

Jerome H. Stone, president of ADRDA, describes the current state of Alzheimer's research:

"Until this year, the battle has been primarily for research monies. We've been very successful on that with an increase in such funds from $4 million in 1976, to more than $50 million in 1985, including funds for 10 multidisciplinary Alzheimer's Research Centers throughout the nation. Now, the battle has shifted to trying to get Congress to focus on the people who have the disease and those who will have it before a cure is found. This is a hard battle because the costs are so great. (Stone estimates that the national Alzheimer's bill in the year 2030 will be $750 BILLION.)

"We're trying to focus on extending Medicare to Alzheimer's patients. We'd like to see a tax deduction or tax credit made available for

the costs of care of an Alzheimer's patient. A 1982 Congressional Budget Office report said that from 10 to 30 percent of people in nursing homes would have been kept at home if there had been some form of tax relief. We'd like to see Veterans Administration care extended and an even policy established. We'd like a Social Security disability insurance program. Alzheimer's patients who are still working when their symptoms begin to show tend to quit their jobs or get fired. When they apply for disability benefits, they're often turned away. The examiners in many states who pass on those claims aren't up to date on the disease. The guidelines should be updated. We're pushing for a separate category for the Alzheimer's sufferer.

"The most recent legislative effort was a bill introduced in the Senate, a comprehensive package dealing with research, discriminatory practices against Alzheimer's sufferers, income splitting. Income splitting is to deal with the situation where one spouse is stricken by Alzheimer's and is eligible for Medicaid only after the well spouse has spent the family income down to the poverty level thus creating two victims. Income splitting would mean that once one spouse was diagnosed as having the disease, the other would be allowed to keep a percentage of the family resources without affecting the patient's eligibility for Medicaid."

Stone urges concerned persons to join the ADRDA organization that is battling for aid to caregivers, to support research, to participate in organized attempts to influence legislators, and to write their senators and representatives. Concluding, he emphasizes, "Let's make sure this once silent epidemic remains in the spotlight and gets attention that is long overdue."

The Good Fight

The war against Alzheimer's disease continues on many fronts—in research labs, in legislative bodies, in support group meetings, in homes and nursing homes all across the country. It is a terribly important fight. The battles are waged to save minds and stave off a national health financing crisis in the future, to ease the awesome burden shouldered by present caregivers, and to honor the memory of those whose memories have been lost, those whose battle is over.

She has misplaced her car keys—
Asked me to find them please;
She's accused me of hiding them
Accused me of losing them,
But I know it's just the disease.

She's forgotten our daughter's name—
And didn't know her when she came;
She called her a stranger
Said she represented danger,
But it's impossible to confront her with blame.

She called me her daddy today—
And said she was going away;
She packed all the groceries
And called a mechanic,
It was hard to convince her to stay.

Her eyes say I don't know her—
But I know I still owe her
For the memory of the years
And the loving and the tears,
I will always continue to show her.

Terry W. Brown
Ferndale, Washington

AARP RESOURCES

The Right Place at the Right Time. A primer on long term care that explains various options, financial arrangements, and eligibility requirements.

Knowing Your Rights. Booklet answers many questions about Medicare's Prospective Payment Sytem.

A Handbook About Care in The Home. Booklet explaining home health care services options and the range of service agencies.

Healthy Questions. Folder containing tips on how to select and talk to physicians, dentists, vision care specialists, and pharmacists.

Your Home, Your Choice. A workbook for older persons and their families to help in making decisions about living arrangement alternatives—from in-home services to nursing home care.

Quackery—The Billion Dollar Miracle Business Flyer briefly describes common health frauds (or quackery), and how to protect yourself.

Insurance Checklist. Guide for the individual to help determine personal insurance needs and compare prices for auto, life, health, and residential insurance.

To receive a single free copy of any of these publications, send a postcard addressed to (Publication Title), AARP Fulfillment, 1909 K Street, NW, Washington, DC 20049.

ADDITIONAL RESOURCES ON ALZHEIMER'S

Alzheimer's Disease—Report of the Secretary's Task Force on Alzheimer's Disease. 1984. U.S. Department of Health and Human Services. Washington, DC. 107 pp. Gives information on demographics, research, diagnosis, treatment, use of drugs for secondary symptoms. Section on systems of care, i.e., services available, including day care programs, homemaker services. Information on training personnel and dissemination of educational materials. References. Available from Superintendent of Documents, U.S. Government Printing Office. Washington, DC 20402.

Aronson, Miriam K., Ed.D., and Jarvik, Lissy, M.D. *Generations*. Fall 1982. Vol. 7 (1) 64 pp. Western Gerontological Society. San Francisco, CA. The entire issue of this quarterly publication was devoted to the subject of Alzheimer's disease and contains almost 20 articles on various aspects of the disease—the patient's right to know, research, genetics, institutional care, support groups, proposed policy changes and a feature on a special nursing home unit. In the Afterword, there is mention of day care and other respite alternatives. Each article has references. *Available through ADRDA for $4.85.

Aronson, Miriam K., Ed.D., and Katzman, M.D., eds. *Generations*. Winter 1984. Vol. 9 (2) 72 pp. Western Gerontological Society. San Francisco, CA. The entire issue is devoted to an update of the research, treatment and diagnosis of Alzheimer's disease. A summary of the Mace and Rabins survey of adult day care centers and guidelines for families seeking public assistance. One article outlines a caregiver education program in Minneapolis. Another describes a training program for volunteers giving respite and briefly mentions the Lexington, Kentucky, day care program. Each article has references. Available from the Western Gerontological Society. 833 Market St. Room 516, San Francisco, CA 94103 for $7.

Cohen, Donna, Ph.D., and Eisendorfer, Carl, Ph.D., M.D. *Loss of Self: A Family Resource for the Care of Alzheimer's Disease and Related Disorders*. 1986. W.W. Norton Company, New York, NY. A sensitive, well-written book by two highly experienced professionals. It contains a wealth of case history material and accurate medical and research information. The book is an excellent resource on Alzheimer's disease for caregivers, family and friends of Alzheimer's disease victims, and valuable to professionals as well.

Fisk, Albert A., M.D. *A New Look At Senility—Its Causes, Diagnosis, Treatment and Management*. 1981. Charles C. Thomas. Springfield, IL. 103 pp. Includes demographic data, sections on diagnosis, care at home, nursing home placement. Brief description of Alzheimer's disease and related disorders. Suggests use of such programs as Meals on Wheels, the caregiver's need for respite, need to develop day care, use of homemaker services. Discusses choosing a nursing home, use of reality orientation. Available from Charles C. Thomas. 301-327 E. Lawrence Ave., Springfield, IL 62703.

Hanley, Ian and John Hodge, eds. *Psychological Approaches to the Care of the Elderly*. 1984. Croom Helm: London Methuen: New York, NY. 282 pp. Addresses specific problems of dementia and depression. Discusses the quality of life in an institution. Section on reality orientation therapy—who benefits, how to use it, methods—particularly as it relates to dementia patients, includes a model

and guidelines for implementation and suggests that a day care center is the ideal setting. References. Available from Methuen. 733 Third Ave., New York, NY 10017.

Henig, Robin M. *The Myth of Senility: Misconceptions About the Brain and Aging*. 1985. AARP Books, Washington, DC, Glenview, IL. 336 pp. Focuses on Alzheimer's Disease with a look at possible causes, means of diagnosis, use of medications. Discusses environmental influence on behavior. What to do to minimize disability, caused by senility, at home. Describes faults of institutions and use of short-term institutionalization. Available from AARP Books, Scott, Foresman and Company, 400 South Edward St., Mount Prospect, IL 60046 for $14.95 ($10.85 for AARP members).

Heston, Leonard L. and June A. White. *Dementia—A Practical Guide to Alzheimer's Disease and Related Illnesses*. 1983. W.H. Freeman and Co. New York, NY. 163 pp. Written for the lay reader, this book includes sections on signs and symptoms, possible causes, means of diagnosis and genetic risks. Contains samples of psychiatric tests used in diagnosis, where to write for vital records, information on how to select a nursing home, dealing with insurance, legal matters and social security. Available through ADRDA for $11.45.

Horne, Jo. *Caregiving: Helping an Aging Loved One*, 1985. AARP Books, Washington, DC Glenview, IL. A comprehensive and realistic look at the role of the caregiver, with practical advice and sound information on providing living arrangements, handling financial and legal matters, and getting help from others. Available from AARP Books, Scott, Foresman and Co., 400 S Edward St., Mount Prospect, IL 60056 for $13.95 ($9.95 for AARP members).

Mace, Nancy L. and Peter V. Rabins, M.D. *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses and Memory Loss in Later Life*. 1981. Johns Hopkins University Press. Baltimore, MD. 245 pp. Contains practical suggestions for learning to live with and care for a victim of dementia. Explains dementia and the management of a dementia victim, the changes to expect in lifestyle and in everyday life, including hazards to watch for and changes in family relationships. Outlines legal and financial factors to consider and offers a guide to selecting a nursing home or other living arrangement. Brief mention of day care. Extensive references and additional sources of information. Available through ADRDA for $8.45.

McDowell, Fletcher H., M.D., ed. *Choosing a Nursing Home for the Person with Intellectual Loss*. 1980. The Burke Rehabilitation Center. White Plains, NY. 13 pp. To help those who must select a nursing home for someone with dementia, so that the result is good, 24-hour care and protection for the patient. Examines when, where and how to select. Includes sections on meeting the costs, conservatorship, day of admission, subsequent visits. Lists additional sources of information and references. Available through ADRDA for $1.25.

McDowell, Fletcher H., M.D., ed. *Managing the Person with Intellectual Loss at Home*. 1980. The Burke Rehabilitation Center. White Plains, NY. The editor says this is "an encyclopedia of information" for the caregivers of adults with progressive memory loss. Specifically addresses the problems created by Alzheimer's disease. Suggestions include aids for memory, bathing and grooming, incontinence, dressing, exercise, legal matters, nighttime supervision, respite for the family. Lists sources of help. Available through ADRDA for $1.75.

Q & A: Alzheimer's Disease. 1981. U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health. Describes disease, symptoms, diagnosis, research, possible causes and treatments. Available through ADRDA for $.75.

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38